

SOCIAL MEDIA AND PALLIATIVE MEDICINE: A RETROSPECTIVE TWO-YEAR ANALYSIS OF GLOBAL TWITTER® DATA TO EVALUATE THE USE OF TECHNOLOGY TO COMMUNICATE ABOUT ISSUES AT THE END-OF-LIFE

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ABSTRACT

Background

Social media describes technological applications which are used to exchange information in a virtual environment. The use of social media is increasing, in both professional and social contexts, on a variety of platforms such as Twitter®; however, the scope and breadth of its use to discuss end-of-life care has not previously been reported.

Aims

To determine the frequency, sentiment and trend of Twitter® 'tweets' containing palliative care related identifiers (hashtags) and/or phrases sent by users over a two-year period.

Methods

A two year retrospective analysis of Twitter® posts (tweets), between the 1st August 2011 to 31st July 2013, using a social media analytics tool: TopsyPro®. Thirteen search terms were identified and analysed for tweet volume, frequency, sentiment and acceleration.

Results

A total of 683.5K tweets containing a combination of 13 palliative care terms were analysed. The tweet volume for all terms increased by 62.3% between 2011-2012 (262.5K) and 2012-2013 (421K). The most popular terms include 'end-of-life' (210K), #hpm (114K) and 'palliative care' (93.8K). Sentiment was high with 89% of tweets rated more positive than all other tweets sent on Twitter® during this period. The term 'Liverpool Care Pathway' experienced the highest percentage increase in tweets (55% increase) reaching a peak in July 2013.

Conclusion

A lot of discussion about palliative care is taking place on Twitter®, and the majority of this is positive. Social media presents a novel opportunity for engagement and ongoing dialogue with public and professional groups.

BACKGROUND

The term Social media describes technological applications which are used to exchange information in a virtual environment.[1, 2] This form of communication, for many, is an integral part of normal life with website likes Facebook®, Twitter® and Google+® providing a platform for discussion. Increasingly, social media platforms are used to facilitate discussions about end-of-life care issues.[3] Examples include the Twitter® page of Dr Kate Granger, a young doctor who tweets about her life as a cancer patient. Her profile has over 25,000 followers from a wide range of backgrounds.[4] Consequently, the social media genre presents an opportunity for society, from healthcare professionals to lay members, to engage in a mutual discourse about death and dying.[5-7]

Despite this interest in palliative care social media, to date, there is a lack of literature about its frequency of use over time, the content of this discussion and the tone of dialogue (for example, whether the debate is positive or negative). Concerns regarding the potential for bad publicity, confidentiality issues and complaints have led to organisations like the General Medical Council and the British Medical Association urging caution on the use of social media.[8, 9] However, as the use of social media for day-to-day communication becomes more prevalent in society there is a need for greater clarity about the acceptable and appropriate levels of engagement for healthcare professionals and organisations.

Commercially, many organisations use social media applications to manage their brand identity and reputation.[10] Accordingly, many businesses use analytical software to capture data, predict behaviour of customers, analyse sentiment, identify influential people and create targeted advertising campaigns.[11, 12] This technology was used for political purposes during a six-week period of the 2012 USA presidential election campaign. The

analysis provided information about the popularity of the candidates to predictions about the voting preferences of the electorate. [13] Despite this corporate and political use of social media analytics software, it is less commonly used in a strategic fashion by healthcare and academic organisations to evaluate opinion/performance (e.g. by analysing patient feedback[14]), establish patient and public involvement (in order to develop services), or to target specific individuals (e.g. for recruitment to research[15, 16]). Consequently, there is the potential to use analytical software to gain a greater understanding about the use of social media in palliative care; however, this requires further study.

AIM

The aim of this study is to use social media analytics software to determine the frequency, sentiment and trend of Twitter® ‘tweets’ containing palliative care related hashtags and/or phrases sent by users over a two-year period.

METHODS

Twitter® is an online social networking and micro-blogging service that enables its users to send and read text-based messages of up to 140 characters, known as ‘tweets’. Twitter® users can prefix a keyword with a hashtag (#) allowing users to ‘tag’ the message to a particular subject of interest. Twitter® was chosen to conduct this analysis due to its high prevalence of use and acceptance by society as a popular mainstream method of digital mobile communication. Twitter has 255 million monthly active users, 77% of which are outside the USA, sending approximately 500 tweets per day.[17] Furthermore, Twitter is increasingly used by celebrities,[18] members of society,[19] academics,[20] television companies[21] and businesses[22] as a primary method of social discussion and

engagement. Additionally, in contrast to other platforms, every tweet sent from Twitter© (since its creation in 2006) is searchable through use of the social media web analytics tool, TopsyPro©.[23] TopsyPro© is a real-time search engine powered by the Social Web which (unlike traditional web search engines) indexes and ranks search results based upon the most influential users' conversations based on each specific term, topic, page or domain queried. TopsyPro© also provides metrics about the frequency, overall tone (sentiment) and change in use (acceleration) of individual search terms in the individual search terms used in the tweet messages. In light of this we felt that analysis of Twitter© through TopsyPro©, offered the opportunity to study this popular social media platform, in order, to improve the understanding of communication using this technology in the palliative care arena. This will hopefully facilitate future analysis across other social media platforms (e.g. Facebook©) and internet search databases (e.g. Google©).

We conducted a retrospective analysis of Twitter© of all tweets sent between the 1st August 2011 to 31st July 2013 using TopsyPro©.[23] Hashtags and search terms were identified from commonly used terms and use of an online hashtag finder.[24] Thirteen search terms (Table 1) were identified and analysed for tweet volume and frequency, sentiment and acceleration.

The TopsyPro© sentiment algorithm relies on a large lexicon of sentiment-carrying words in addition to grammatical rules and other heuristics. The score is primarily based upon a list of words known to normally be used in a positive or negative context. The method follows a standard approach employed in other sentiment analysis packages, where a positive or negative score are given to terms based upon the polarity and strength of the term (for example, love and hate scores would be polarised at opposite ends of the scale).[25, 26]

Sentiment programs will check for the presence of sentiment terms from its lexicon and predicts the sentiment of those terms based upon the scores of the words found in the rest of the tweet. For example, the term 'love' is weighted differently for a sentence reading "I love you" compared to the phrase "I love to hate you". As the overall sentiment of the latter sentence is negative, the term 'love' is scaled to score with more negativity/ neutrality compared to its positive usage in first sentence.[25] Scores for individual terms are scaled to make it possible to compare overall sentiment between them. Scores range from 0 to 100, with 0 being the most negative, 50 being neutral, and 100 being the most positive. [Peter Smith – TopsyPro© support, personal communication, 3rd June 2014]. The sentiment score can be thought of as a percentile score; this means that if a term has a score of 80, tweets about that term were more positive than roughly 80% of all other terms mentioned on Twitter that day.[13] Acceleration has a range from -100 to +100 and rates the change in search term usage; where 0 indicates no change in search term use and negative scores suggest decreasing use and discussion. Where possible, the geographical location of tweets was recorded.

Table 1: Table of the hashtags and search terms used in the social media analysis

Search terms	Explanation
#hpm	Hospice and palliative medicine
#hpmglobal	Hospice and palliative medicine global
#eolc	End-of-life care
#eol	End-of-life
#hospice	Hospice
#palliative	Palliative care

Supportive care

End of life care

End of life

Palliative care

Palliative medicine

Hospice care

Liverpool care pathway*

Liverpool Care of the Dying Pathway

*The hashtag #LCP was not used in this analysis as this was found to vary in meaning and use in different countries.

RESULTS

A total of 683.5K tweets containing a combination of 13 palliative care terms were sent on Twitter© during the two-year analysis period (Figure 1). Tweet volume for all terms increased by 62.3% between the '2011-2012' (262.5K) and '2012-2013' (421K) time points. The most popular terms include end-of-life (210K), #hpm (114K) and 'palliative care' (93.8K). (Figure 2) Sentiment was high as 89% of terms were classified as more positive than all other terms mentioned on Twitter© during this period (Figure 3). Regarding acceleration, the term 'Liverpool Care Pathway' experienced a 55% increase (Figure 3) reaching a peak in July 2013 (Figure 1), followed by #hpmglobal (33%), #eol (23%), 'end of life care' (23%), #eolc (15%) and 'end of life' (15%). The lowest scores were noted for the terms 'palliative' (6%), 'hospice care' (3%) and 'palliative medicine' (0%). Geographic origin of tweets was only available for the 2011-2012 periods (Table 2). Tweets were sent from several

continents across the world, with the greatest volume of activity seen in English speaking countries (USA, 58.1%; UK 21.8% and Canada, 6.6%).

Figure 1 - Line chart displaying the total volume of Twitter® tweets sent using different palliative care orientated search terms and hashtags 2011 - 2013

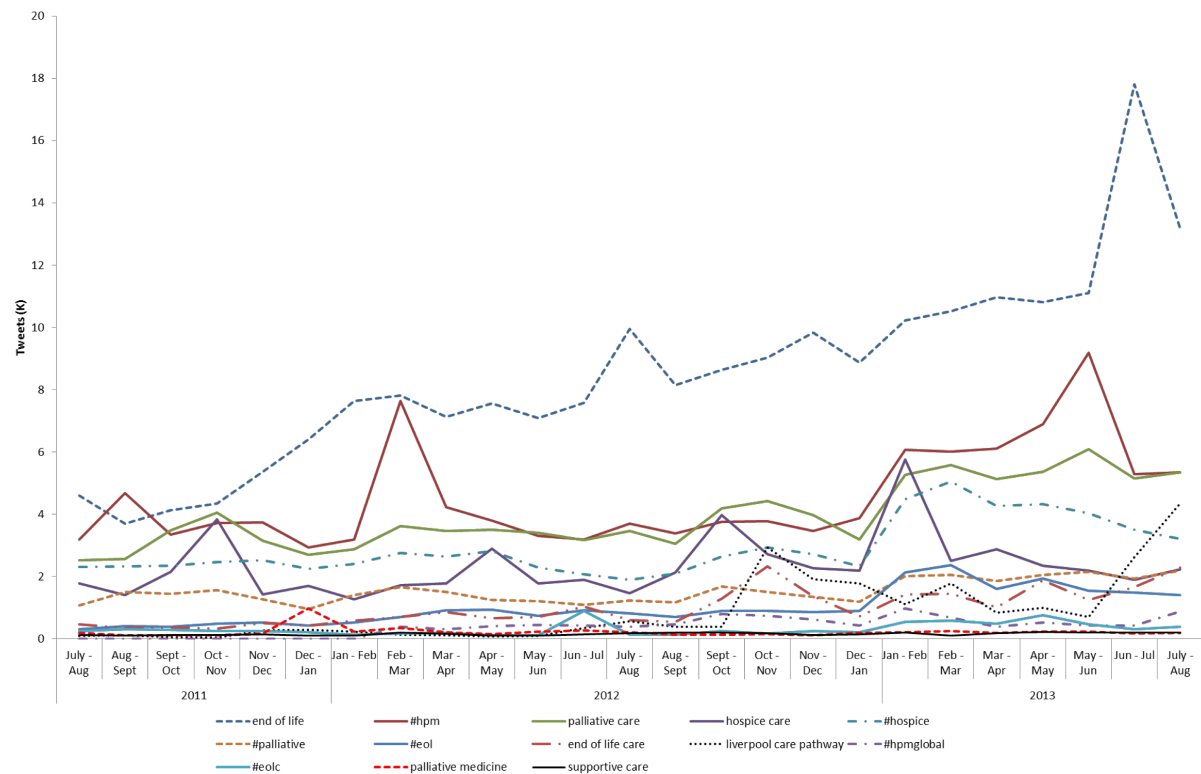


Figure 2 - Bar chart displaying total number of tweets by search term (2011 – 2013)

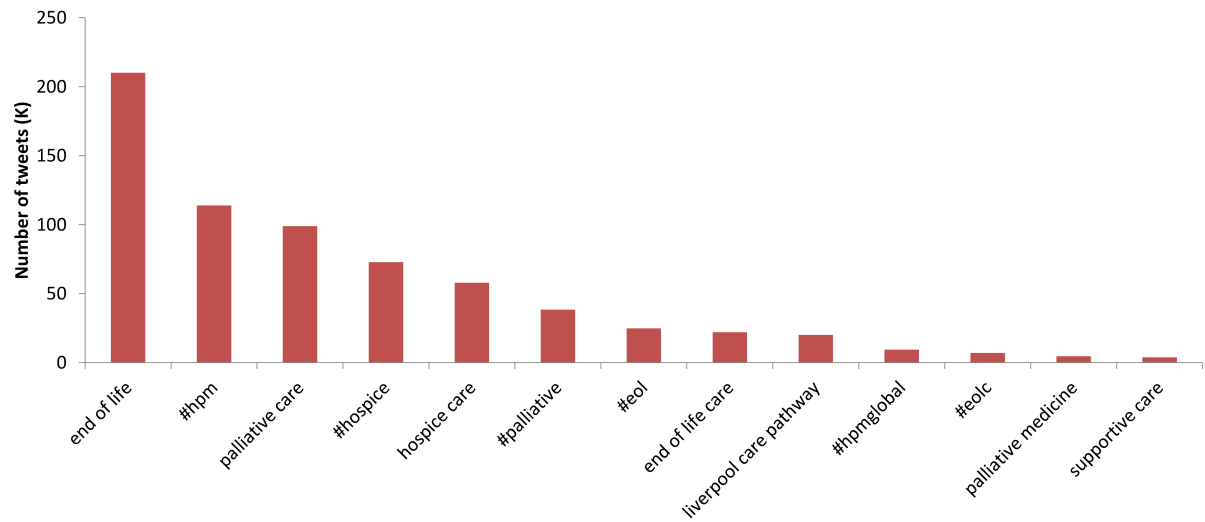


Figure 3 - Bar chart displaying sentiment and acceleration scores

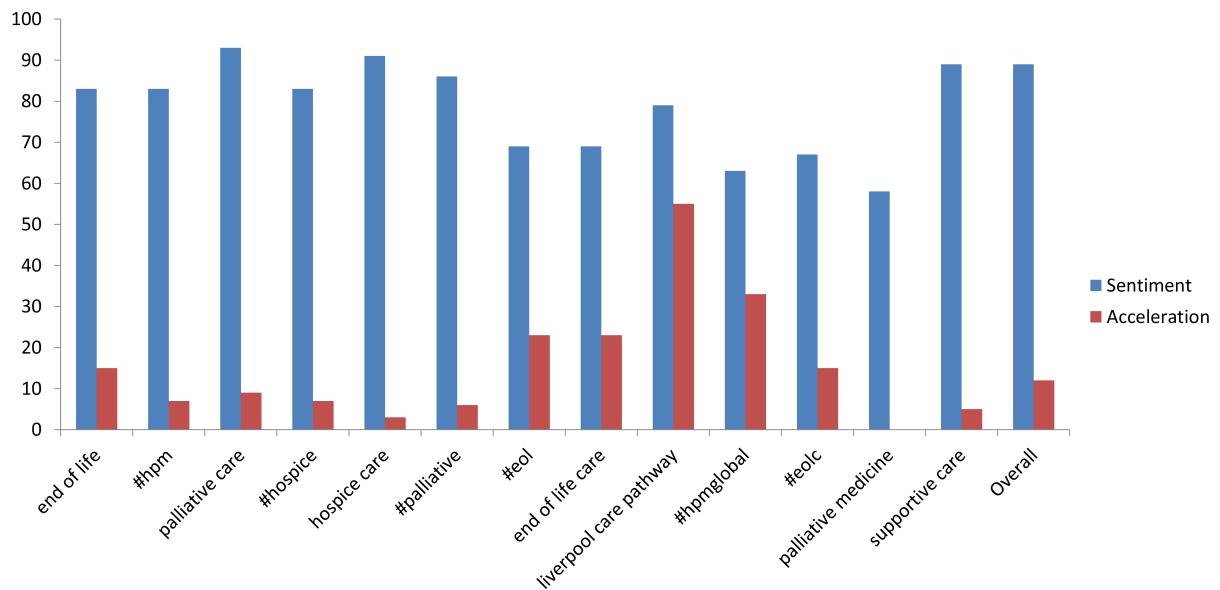


Table 2: Percentage of tweets by geographical location of countries using the search terms with the greatest frequency (2011 – 2012)

Country	Percentage of tweets (%)
United States of America	58.1
United Kingdom	21.8
Canada	6.6
Thailand	2.3
Australia	2.3
Netherlands	2.0
Vietnam	1.7
Philippines	1.4
Argentina	1.2
Spain	1.1
Trinidad and Tobago	1.0
Others	0.5

DISCUSSION

Main findings

This analysis demonstrates that, on Twitter®, the use palliative care related search terms and hashtags has increased over the past two years, reaching a peak in July 2013 which coincided with the Neuberger review into end-of-life care in the United Kingdom.[27] The

majority of tweets were positive in nature with most activity centred in Western English speaking countries.

What makes this study unique?

This study, to our knowledge, is the first to use analytical software to evaluate the nature of palliative care discussion on a social media platform. This study is unique in presenting a two-year capture of every Twitter© tweet sent worldwide. Furthermore, it is the first study to provide information concerning the sentiment and the geography of palliative care discussion on Twitter©.

Limitations

This study has several limitations. Firstly, only English search terms were included in the analysis. Therefore, it is possible that potentially relevant tweets originating in different languages were missed. Furthermore, search terms differ in significance according to their cultural context. For example, the hashtag #LCP, an abbreviation for the Liverpool Care of the Dying Pathway in the UK, denotes a political television company in France (i.e. La Chaîne parlementaire).[28] Although some data for the geographical location of tweets is presented, data for the last year of analysis was unavailable. Additionally, only geographical data for tweet volume was available for this analysis as opposed to the geographical variations of the individual search terms.

No demographic information of tweeters was available for analysis. Consequently, it is not possible to determine how representative of society this analysis is. Although social media has a wide spectrum of users, previous data suggests Twitter© is most popular amongst younger adults aged 18-29.[29] However, it is important to acknowledge that the continual

integration of technology into daily life will continue and younger members will require palliative care services in some form (whether as users or carers) in the future.[30]

In total, thirteen search terms were chosen due to their overall frequency of use across the data collection period. However, some search terms with low levels of use throughout the year have considerably higher use at certain time points (for example, around academic conferences[20]). Further study of these search terms (in combination with other search terms not featured in this analysis), with reference to calendar reasons for variation, may provide more information.

Only data up to July 2013 was reported. This coincided with the release of the findings from the Neuberger review;[27] it is possible that the frequency and sentiment of tweets may have been influenced as a result of the published review findings. A longer analysis may have provided useful information about the nature of the discussion in the time period after this event. Many different social media platforms are available (e.g. YouTube®, Facebook®) which may carry useful information for this discussion, however, this study chose only to provide analysis of Twitter®.

Although sentiment is able to provide a general sense of the tone of a term (i.e. positive, negative or neutral) we do not have information about the content of the tweets.

Consequently, it is not possible for us to distinguish between tweets which were explicitly negative about the selected keywords and those that, although negative, were not (and vice versa with positive tweets). For example, a negative tweet reporting poor care may include palliative terms to demonstrate how care can be improved, rather than suggesting that palliative care is somehow undesirable. TopsyPro® scores sentiment, for selected search terms, comparatively to all other tweets sent in the study period. Consequently, it is

possible that the analysis may be influenced by the overall tone of tweets posted by Twitter users (e.g. inherently positive or negative).

What is the significance of the findings of this analysis?

Death, dying and end of life care are still perceived as ‘taboo’ subjects that are difficult to discuss openly. However, despite the limitations, the evidence from our analysis would suggest that discussion in this area is frequent, increasing in volume and largely positive. We have no way of knowing who is ‘tweeting’; whether the tweets are largely from healthcare professionals or members of the public. However, the volume of discussion suggests that social media platforms may provide a mechanism to engage with this nuanced and traditionally difficult area.

The increasing use of social media applications is consistent with other reports and this trend shows no signs of abating.[29] It can be argued that the use of these networks is not a temporary phenomenon but represents a permanent change in the nature of communication.[12] The evolving nature of communication is not unique; several comparisons can be drawn from history (e.g. the printing press, the telephone and email).

There are calls to improve the societal debate of end-of-life care and facilitate greater patient and public involvement in research.[31] Use of social media provides the opportunity to participate in a discussion which is already taking place; many members of society are already comfortable with this form of communication, even if healthcare professionals are not. It can be argued that the form of communication should not be a barrier for dialogue if doing so would allow for meaningful engagement into end-of-life care issues.

There is reluctance, in some settings, to fully realise the potential that social media has to assist with healthcare related communication. For example, the public consultation for the Neuberger review into end-of-life care did not feature the use of social media in its engagement strategy.[27] However, the data from this study demonstrates that a lot of discussion concerning end-of-life care was already taking place on Twitter®, highlighted by an increase in tweet activity following the release of the final report in July 2013. This corresponded with a sharp increase for the 'Liverpool Care Pathway' term which also experienced the highest acceleration of all terms evaluated. A moderate increase in acceleration was noted for #hpmglobal, a popular hashtag for the worldwide palliative care community. Several reasons may exist for the change of use (or non-use) different terms over time. These may include language considerations, length of the search term, similarity to other hashtags (and phrases) and the use of the specific terms by influential Tweeters. This exercise has demonstrated the potential to evaluate the use of specific Twitter® terms within a defined time period; however, further analysis, over a longer duration, may be needed to evaluate patterns of activity concerning the use and choice of terms.

Future opportunities and research possibilities

The continued integration of social media (and other forms of technology) into routine life presents several opportunities.[30] For example, many television and entertainment systems are pre-installed with social media applications and video communication software (e.g. Skype®), providing the public with accessible forms of this technology. Consequently, it is possible that these devices can be utilised to engage households directly[32] (e.g. through development of software and/or optimisation of existing applications) in addition to personal computers and mobile devices.[30] Future research can examine how the public

and healthcare professionals can be engaged through social media (and other forms of technological communication) to improve palliative care services and involvement in research. Studies can evaluate other social media platforms with reference to current (and historical) events to determine the degree of discussion for end-of-life related issues.

CONCLUSION

A lot of discussion about palliative care is currently taking place on Twitter®, and the majority of this dialogue is positive. Social media platforms present a novel opportunity for engagement and ongoing dialogue with public and professional groups about palliative care. Further in-depth quantitative and qualitative analysis of the nature and impact of this form of digital communication is required as the increasing use of this media is likely to increase and engage wider society.

CONTRIBUTOR STATEMENT

AN designed study, conducted the analysis, interpreted the results and wrote the paper. MD and CR assisted with the data analysis and provided critical review of the final manuscript. SM provided support of the conduct of the project as a whole and provided critical review of the final manuscript.

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COMPETING INTERESTS STATEMENT

None declared.

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